A Comprehensive Local Program for the Prevention of Fetal Alcohol Syndrome

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Synopsis

A hospital based, comprehensive approach to the prevention of Fetal Alcohol Syndrome and Fetal Alcohol Effects that combines clinical assessment, community outreach, and epidemiologic knowledge to attack alcohol-related birth defects is described. The program includes training of clinicians and members of the community, baseline screening of suspected children, and alcohol consumption screening of pregnant women in prenatal clinics.

The major, although not exclusive, focus of the program is on tertiary prevention undertaken with women defined as "high risk" for producing alcohol affected children.

Of the 48 women referred to the program at the Tuba City, AZ, Indian Medical Center between January 1988 and July 1989, 39 (81 percent) became participants. Complete followup was possible on 31; 17 of them reported alcohol abstinence in July 1989, 18 months into the program.

Of the 29 referred women who were pregnant at the time, 21 agreed to particpate; of these, 19 (85.7 percent) were abstinent by the third trimester of pregnancy; 5 voluntarily accepted offers of contraceptive measures after the birth of their child.

FETAL ALCOHOL SYNDROME (FAS) has been called the most common, best known, most preventable cause of mental retardation in the western world (*1*). First described in the medical literature in the United States in 1973, the syndrome is caused by a pregnant woman's heavy use of alcohol (*2*). Diagnosis is based on the presence in infants of retarded growth, a pattern of facial abnormalities, and abnormalities of the central nervous system, including mental retardation (*3*). Lower levels of alcohol use may produce Fetal Alcohol Effect (FAE) or Alcohol Related Birth Defect (ARBD) that can include mental deficit, behavioral problems, and milder abnormal physiological manifestations. These effects are less easily recognized or diagnosed than the full-blown syndrome (*4*). There is no known cure for FAS or other alcohol-related birth defects. Prevention, therefore, is of paramount importance.

While many studies have been published on the variety and range of the teratogenic effects of alcohol on the fetus, few have described successful methods of preventing them (*5*). Given the substantial limitations of children damaged by alcohol (*6*), there is a need for aggressive programs of intervention and prevention (*7*). A reduction in the incidence of FAS by 25 percent was one of the Public Health Service's "Objectives for the Nation" published in 1980 (*8*).

Any study of the outcome of prevention efforts is hampered by the fact that the baseline incidence and prevalence of FAS in the United States is not precisely known (*9*). In addition, monitoring the progress of prevention efforts for a large and diverse population such as that of the United States is difficult, if not impossible, under current conditions. It is necessary, therefore, that more easily monitored local programs be pursued.

The overall prevalence of FAS in the United States is generally estimated by a number of studies of particular populations, most of which use clinic based estimates. Currently, these studies indicate that the incidence may be between 1.3 to 2.2 per 1,000 live births (*9,10*). For example, the incidence in Seattle has been found to be between 0.4 and 3.0 per 1,000 and in Boston between 0.6 and 3.1,

depending on the subpopulation in question (*10*). Many questions remain regarding issues such as clinical bias, social class as it affects both incidence of FAS and the use of the participating clinics, and other matters which limit the generalizability of these estimates. Until a more general incidence figure is established for the United States, monitoring the progress of the prevention of FAS is a problem.

The specific program we describe, the Tuba City project, has the potential of determining accurately the outcome or impact of the prevention activities because it is in a location that is advantageous for studying change in incidence.

The Tuba City Service Unit of the Navajo Area of the Indian Health Service (IHS) serves more than 20,000 Navajo and about 1,000 Hopi Indians who reside in the westernmost portion of the main Navajo and Hopi reservations. The service unit participated in the initial IHS Fetal Alcohol Syndrome Pilot Project (*11*) that established a baseline prevalence using a population-based screening procedure (*12*).

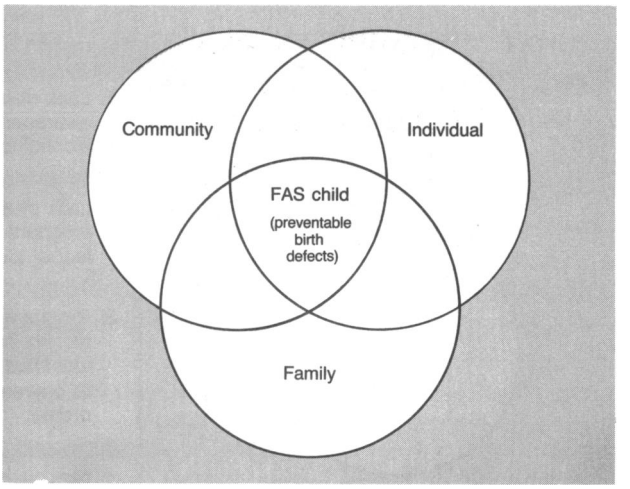
In the initial screening, the prevalence of FAS in the Tuba City Service Unit was found to be 1.3 per 1,000 population in 1982 for children younger than 15 years; in children ages 0–4 years, FAS was 2.7 per 1,000. The prevalence of FAS and FAE combined in children ages 0-4 was 3.7 per 1,000 (*11*). This meant that the problem was found to be slightly higher than in the estimates for the general population, and it was growing (*10*).

On several different occasions from 1982 to 1985, FAS lectures and prevention workshops were held in Tuba City for the specific purpose of educating local health care providers and a broad spectrum of advocates in FAS prevention (*11*). In spite of these awareness efforts, very few organized and consistent FAS activities were undertaken.

Methods

By 1987, the practitioners caring for pregnant women and children in the Tuba City Service Unit were disturbed by the lack of a protocol for treating pregnant alcohol-abusing women. Additional resources to address the problem were obtained from the Indian Health Service, which funded the Tuba City FAS Prevention Project for fiscal year 1988 as a Health Promotion-Disease Prevention Demonstration Project. A family physician, a Navajo-speaking prevention worker, and a Navajo-speaking clerk joined the Community Health Services staff to provide a three-pronged approach to FAS prevention that views FAS in a systems perspective, using community, family, and individually based techniques (fig. 1).

Figure 1. Hypothesis of Fetal Alcohol Syndrome (FAS) system

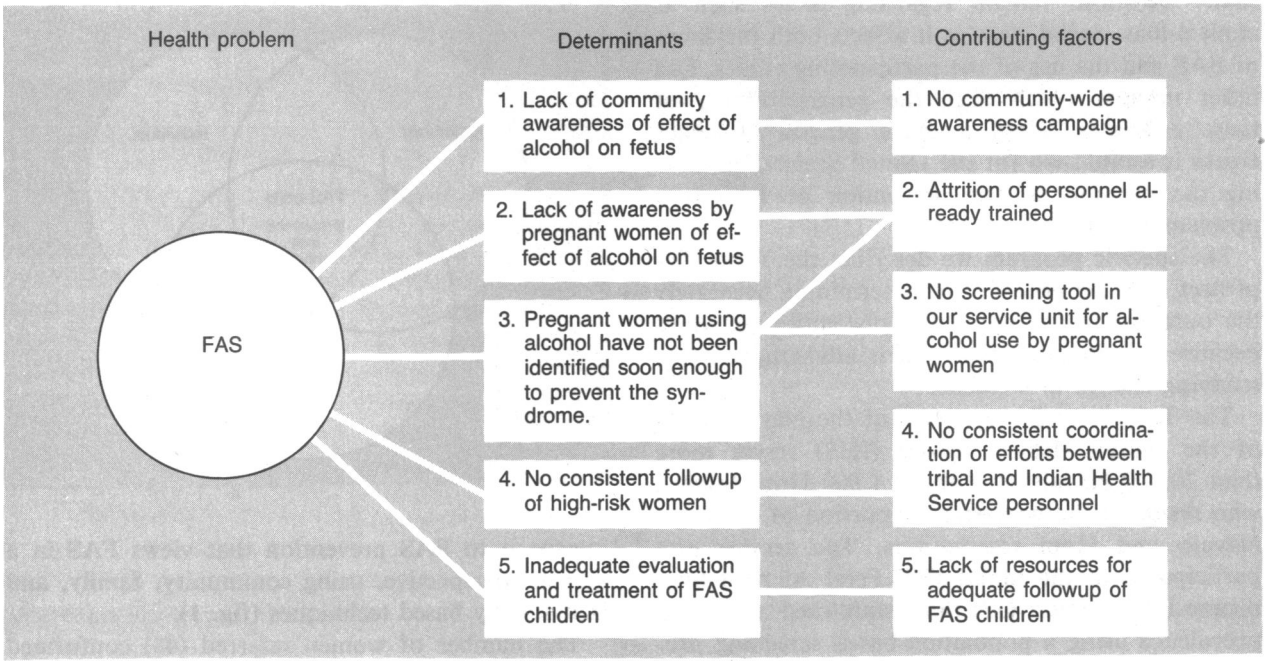


The number of women referred (48) conformed closely to the range projected from maternal risk figures produced from the pilot project rates in 1981–82. In the pilot study, 23 percent of the women who produced a damaged child went on to produce another for an average of 1.3 per mother. The rate of mothers producing all of the FAS and FAE children was found in Tuba City to be 5.9 per 1,000 women of childbearing age from 1978 to 1982 (*12*).

Projecting this number to the current population of women in the Tuba City Service Unit (ages 15 to 44), we estimated that there would be between 25 and 30 women who would be considered at risk for having an FAS-FAE child. The estimate may appear low, inasmuch as drinking among Navajo women has increased (*13*), the rate of FAS-FAE is on the rise, and the program is reaching those women with lower levels of risk (*14*). Nevertheless, the 1978–82 epidemiologic figures have been proven to be relatively accurate and useful for estimating the number of clients.

The Health Analysis for Planning Prevention Programs System (HAPPS) approach was used to analyze the problem and plan objectives and activities (*15*). Implicit in this model is the use of a variety of primary, secondary, and tertiary methods of prevention with a series of impact objectives. As listed in figure 2, these objectives served as the specific guidelines for both activity and evaluation. Stated in terms of primary, secondary, and tertiary prevention, the first two levels of prevention were designed to ensure the functioning of the third.

Figure 2. Fetal Alcohol Syndrome (FAS) planning model



At the primary level, the goal was to increase knowledge and awareness in the community through presentations, posters, pamphlets, media, and through the training of school personnel, participants in the Women, Infants and Children Program, social service and child development workers, alcoholism counselors, and IHS health care providers—all of whom then shared their expertise with others in various segments of the community. This also ensured that community members would be involved in referring clients to the hospital program.

Secondary prevention was accomplished by screening patients in prenatal clinics for alcohol use and providing them with information and education about FAS and alcohol. Those pregnant women found to be heavy drinkers, who continued high risk drinking during pregnancy or were mothers of previous FAS-FAE children, or both, were referred for tertiary prevention.

Tertiary prevention in the program consisted of detailed case management and support of the client, all done with an empathetic approach. Clients received counseling, personal support, and social services. Those medical services offered fell into two categories: (*a*) detoxification, individual and group alcohol treatment, followup, and after care, and (*b*) voluntary birth control or sterilization. Referrals for tertiary prevention were received from the Division of Social Service, the Juvenile Court, and the alcoholism program of the Navajo Tribe; the Departments of Pediatrics, Family Medicine, and Obstetrics of the Tuba City Hospital; and self-referrals.

The screening administered to all prenatal patients consisted of the 10-question drinking history developed at Boston City Hospital that relies on self-reported frequency and amount of alcohol used (*16*). Its use at the hospital represented a major accomplishment in general clinical awareness of alcohol problems. A protocol for providers to use in the management of pregnant women abusing alcohol was also put in place.

An FAS Diagnostic Clinic was held 5 times during the 1 1/2- year period between January 1988 and July 1989. A university based dysmorphologist, highly skilled in the diagnosis of FAS, examined children suspected of having FAS to confirm or deny the accuracy of the diagnosis. Initial counseling of the mother or caretaker regarding the ramifications of the diagnosis was done by the dysmorphologist.

Of the impact objectives (box), the first, second, fourth, and fifth were primary and secondary prevention because they involved training and screening for the population at risk. A total of 147 employees from Navajo and Hopi tribal agencies and the schools were trained in FAS recognition and awareness. More than 2,000 community members participated in these and other presentations, ranging from talks at health fairs, recreational fairs and events, and local government meetings, and

presentations at food distribution sites on "commodity days." These talks were either completely in Navajo or were bilingual. Public service radio spots in Navajo were broadcast by the local station. Newspaper articles, including an interview with a mother who stopped drinking during pregnancy, reached an estimated 30,000 people. The other impact objectives concerned tertiary prevention activities directly.

Results

After the first 1½ years of operation, the FAS program maintained contact with 39 "at risk" women of the 48 that had been referred. No attempt was made to include or exclude women solely on the basis of a quantified threshold of drinks per day. The screening tool was used in conjunction with many other types of evidence, such as social and medical history and alcohol assessment, to determine risk.

The 39 women clients ranged in age from 16 to 41 years. The mean age was 27.2 (see table). This corresponded closely to the average age of 29.7 years of mothers detected in the previous screening programs who had given birth to FAS-FAE children. It indicates that clients are being contacted at an age when intervention may be possible. There were two pairs of sisters among the women referred, evidence that FAS is a concentrated problem and a family problem. One woman who produced an FAS child was a sister of another woman whose FAS case was documented. There are indications that she herself has FAE.

Of the 39 women, 9 have produced FAS or FAE children, 2 have possible FAS or FAE children, and 8 were pregnant 18 months into the program. (Those classified as "possible" are awaiting diagnosis by the dysmorphologist or further testing, or both.) As in the previous study with Indians (*12*), most mothers of FAS-FAE children have had a number of normal children prior to giving birth to a damaged child. The most recent referrals to the program have been of pregnant women without affected children. This practice indicates an increased awareness of those in the referral network.

After 18 months, a "snapshot" was taken of the drinking status of all women who were referred to the program since its inception. Each woman's status was ascertained by the Navajo prevention worker who had been managing the case. In either a clinic visit or a home visit, information was obtained from the client herself and was verified by a family member.

Impact Objectives of the Tuba City, AZ, Fetal Alcohol Syndrome (FAS) Prevention Project

1. Increasing the knowledge of FAS among Navajo Division of Health personnel
2. Training Indian Health Service Tuba City Service Unit (TCSU) providers in FAS
3. Doubling the number of pregnant women from TCSU who complete residential treatment for alcoholism from 1987 to 1988
4. Demonstrating that TCSU officials show a positive attitude change towards the need to educate their constituents about FAS
5. Establishing an effective screening mechanism for alcohol use by pregnant women at TCSU
6. Implementing a protocol for intervention and followup of pregnant women using alcohol
7. Doubling assessment and treatment of FAS children at TCSU
8. Increasing FAS-FAE mothers or caretakers participating in treatment

Some women who had received counseling were found at followup to be drinking lesser amounts of alcohol less frequently than they were before their contact with the program. If these women were not abstaining from alcohol, but had changed their consumption pattern significantly, they were classified in the study as "drinking less."

Of the 39 mothers participating in the FAS Program, 13 had received residential treatment for alcoholism, and 7 were no longer in the service area at the end of 18 months. The drinking status of the 32 who remained in the service area or were in a treatment facility at the end of 18 months is as follows:

- 18 (56.3 percent) were abstinent,
- 4 (12.5 percent) were drinking less, and
- 10 (31.2 percent) were still drinking as heavily as before.

The 11 women who bore an FAS or FAE child had poorer alcohol use outcomes (table). Of these 11 mothers, 3 (27.2 percent) were abstaining from alcohol, 6 (54.6 percent) were still drinking, and 2 were lost to followup in the 18 months. One of the FAS mothers who was drinking heavily, however, requested and received voluntary sterilization after referral to the prevention program. Three of the 11 women became mothers of affected children during the 18-month program period; the other 8 already

Selected characteristics of clients in the Tuba City, AZ, Fetal Alcohol Syndrome Prevention Program

Characteristic	Number	Percent
Age at referral (years):		
19 or younger	4	10.3
20–24	11	28.2
25–29	11	28.2
30–34	7	17.9
35–39	3	7.7
40 and older	3	7.7
Totals	39	100.0
Number of previous FAS/FAE children:		
One	8	72.7
Two	1	9.1
Awaiting confirmation	2	18.2
Totals	11	100.0
Mother has lost custody:		
Yes	13	33.3
No	23	59.0
Unknown	1	2.6
No previous children	2	5.1
Totals	39	100.0
Alcohol status:		
Still abusing	10	25.6
Drinking less	4	10.3
Abstinent	18	46.2
Unknown[1]	7	17.9
Totals	39	100.0
Alcohol status of FAS/FAE mothers:		
Drinking, no birth control	5	45.5
Drinking, birth control	1	9.1
Abstinent	3	27.2
Unknown	2	18.2
Totals	11	100.0
Family planning status:		
Pregnant	8	20.5
Pill, condoms, foam, IUD	4	10.3
Tubal ligation	6	15.4
No birth control	14	35.9
Unknown	7	17.9
Totals	39	100.0

[1] Moved or live out of the service area and were followed only through pregnancy.

had children with FAS or FAE. Of these three, one FAS child was born in the second month of the project, and one in the fifth month. Both of these women were referred to the project after the child's birth. One woman, referred to the program during her second trimester, refused services until after the birth of her FAS child. She subsequently completed alcoholism treatment and delivered a normal infant 1 year later.

At the end of the 18 months, a chart review of the 39 clients and interview by the prevention worker revealed that 8 (20.5 percent) were pregnant, 4 (10.3 percent) were using birth control, 6 (15.4 percent) had voluntary tubal ligations, 14 (35.9 percent) were at risk for another pregnancy, and 7 had moved from the area. Of those who did not use birth control, 33.3 percent said they did so because of traditional Navajo beliefs.

Of the 29 women referred *during pregnancy*, 21 (72.4 percent) were seen before the third trimester and agreed to participate in the program. Of the eight who did not, two were referred to mental health, three refused all services, two moved out of the area, and one was not located prior to delivery. The abstinence rate of the 21 clients who received FAS counseling and intervention during pregnancy was 85.7 percent. Clients referred at the time of pregnancy, therefore, were more likely to accept help with their drinking.

Discussion

In many settings, women who abuse alcohol have been considered social "throw aways," have been ostracized, or have been otherwise stigmatized and left to produce one, two, or more FAS or FAE children before their own alcohol-related death. In Seattle, for example, Streissguth and colleagues found that 75 percent of the mothers of the more severely damaged FAS children were dead 6 years later (*17*). An epidemiologic study among southwestern Indians found 23 percent of all Indian mothers of FAS-FAE children were dead by the time their children were screened for FAS (*12*). Thus FAS prevention efforts hold the additional promise of reducing premature mortality among high risk mothers.

One of the most striking results has been the acceptance of this program by the women referred. Of the 48 women referred, only 3 refused outright to participate. Several clients stated that one reason for the high rate of participation may be that the program was designated as prevention rather than as an alcoholism or social work program. Other authors have suggested that compliance is enhanced by having a program based in a hospital or prenatal clinic (*18,19*).

The program is comprehensive to meet the multiple needs of the clients. The attempt has been made to gain the cooperation of a number of constituencies in the area that can be used for therapeutic and rehabilitative intervention. In fact, FAS prevention activities seem to have raised the awareness in the community about all forms of alcohol abuse, not just maternal alcohol abuse.

Another key element in the acceptance of the program, both by the community as a whole and by individual clients, was the status of the program

staff members as trusted community residents. Their skills in bridging the gap between the dominant culture and the Navajo culture were indispensable in gaining support by the community as well as the cooperation of pregnant clients. Such community leaders have been called "natural helpers" (*20*).

A family-oriented approach has been a strong asset to this program. Not only has it aided in the identification of additional mothers likely to produce FAS-FAE children, but it has fostered an understanding of the problem. As indicated in the literature, alcohol abuse is highly concentrated in some families. This is proving to be true with FAS among the Navajo. Fewer Navajo women drink than women in the overall U.S. population (*13,21*). But drinking, particularly abusive drinking, is concentrated in a minority of families that suffer from a multitude of other social problems (*22*). A substantial number of women who are high risk for FAS-FAE come from families, either immediate or extended, where alcohol abuse is common, even normative. Most of the 39 mothers are known to be adult children of alcoholics and also have spouses or in-laws, or both, who are heavy drinkers.

The effectiveness of this program depends not only on knowledge, case finding, and treatment efforts both inside and outside the clinic and hospital, but also on the involvement of multiple constituencies in the community. Although this is very appropriate for the Navajo population of Tuba City, it may well be useful for other settings. Certainly a similar program can be considered for other locales. The problem of alcohol-related birth defects will not be eliminated by broadly focused, single faceted programs such as health education. Neither will clinic-based programs succeed without outreach, case funding, and some community awareness. Programs must focus on high risk groups as well as on prevention in a larger arena (*7,23*).

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